

The meaning of suffering in patients with advanced progressive cancer

Jackie Ellis, Mark Cobb, Tina O'Connor,
Laurie Dunn, Greg Irving and
Mari Lloyd-Williams

Abstract

Background: There is a lack of research into suffering and what it means to the individual patient with advanced cancer and its importance in end of life care.

Aims: To explore the concept of suffering and distress by eliciting what individual patients with advanced cancer perceived as suffering and how they utilised their own resources to manage suffering.

Method: A qualitative study design of focused narrative interviews analysed by thematic analysis was conducted with a heterogeneous sample of 49 palliative day care patients.

Results: For those patients who perceived they were suffering, this study revealed a wide spectrum of definitions which could be described within the following areas; the unavoidable and avoidable suffering, physical and emotional suffering, suffering as loss and finally transformation through suffering.

Conclusions: These findings provide important insight that broadens and enriches our understanding into the concept of suffering and how patients utilise their resources, which may have important implications for end of life care.

Keywords

Qualitative, cancer, suffering, end of life, palliative, advanced disease

Received 6 August 2014; accepted 2 December 2014

Introduction

The alleviation of suffering is the central goal of palliative care.¹ Many authors have defined suffering – two definitions include; ‘experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person

Academic Palliative and Supportive Care Studies Group (APSCSG), Institute of Psychology Health and Society, University of Liverpool, UK

Corresponding author:

Mari Lloyd-Williams, Academic Palliative and Supportive Care Studies Group (APSCSG), Institute of Psychology Health and Society, University of Liverpool, Block B, 1st Floor, Waterhouse Building, Liverpool L69 3GB, UK.

Email: mlw@liv.ac.uk

as a complex social and psychological entity² and a 'state of severe distress, subjective and unique to the individual, arising from the perception of threat to one's integrity as a biologic, social, or psychological being'.¹

Although pain and suffering have been connected there is also evidence that they exist independently.²⁻⁴ In a study of patients with cancer,⁴ suffering was found to exist in three dimensions – physical, psychological and social. Physical suffering included fatigue, pain and side effects of chemotherapy. Psychological suffering most often included depression and was related to the physical changes resulting from disease and overall debilitation as death became imminent. These physical and psychological effects caused withdrawal and isolation, leading to the third dimension, social suffering. Daneault et al.⁵ studied the nature of suffering in 26 terminally ill cancer patients and again found three dimensions: physical, psychological and social well-being. Benedict⁶ in a study of patients with lung cancer, found 63% reported moderate to extreme level of suffering. The strongest association was with physical symptoms (60%) and the sources of greatest suffering were disability, pain, anxiety, changed daily activities and weakness/fatigue.

Baines and Norlander³ examined the relationship between terminally ill hospice patients' pain and their physical, spiritual, and personal or family suffering and found that more patients experienced suffering rather than pain. Data from this study indicated that patients view pain and suffering as separate entities. Wilson et al.¹ studied suffering in people with advanced cancer and found that almost half (49.3%) of respondents did not consider themselves to be suffering, with 25% feeling their suffering was mild and a further 25% describing their suffering as severe. In qualitative narratives, physical problems accounted for approximately half (49.5%) of patient reports of

suffering, with psychological, existential and social concerns accounting for less than 20%. They concluded that many patients with advanced cancer do not consider themselves to be suffering; however, for those who do, suffering is a multidimensional experience related most strongly to physical symptoms, but with contributions from psychological distress, existential concerns and social-relational worries. It is of note that more than half of those who reported moderate to extreme levels of suffering had significant depression or anxiety disorder. The uncertainties that accompany a terminal prognosis and subsequently an existential crisis often culminate in an adjustment disorder with anxiety.⁷ Existential distress has been viewed as a threat to the intactness of a person² and a consequence of a paucity of life meaning.⁸

Hopelessness is associated with significant suffering, the desire to hasten death⁹ and suicide ideation; it's related to loss of purpose meaning or value in life and existential suffering, even more than depression.¹⁰ Based on this Kissane et al.¹¹ describe the demoralisation syndrome, a condition characterised by existential distress, loss of meaning, hopelessness, helplessness and difficulty coping with life-limiting illnesses.

The loss of dignity can frequently result in suffering and a desire for hastened death. However, only recently has the personal sense of dignity been systematically studied. A consistent model has now been developed.¹²⁻¹⁴ Terminal cancer patients often associate their loss of dignity with feeling a burden on others and the perception of being treated with respect. Other factors found to influence the decision to hasten death are: issues with social support and concerns about dependency on others.^{15,16} Therapeutic relationships centred on focused on treating the person and not the disease to help conserve or restore the patient's dignity through caring attitudes,

behaviours and dialogue as described by Chochinov.¹²

There is also a breadth of literature on the experience of living with a chronic illness, including the impact on personal and social identity.^{17–21} Much of this has been strongly premised on an argument that illnesses such as cancer disrupt the stories that people tell about themselves. This process constitutes a biographical disruption in that our person narratives are seen as an essential part of our self-identity.²² From this perspective, 'Illness represents change and therefore constitutes a potential threat to maintenance of a coherent self'. In this way, illness is seen as a disruptive event (p.179).²³

To summarise the experience of suffering varies, but much research has demonstrated similar dimensions of suffering i.e. physical, psychological, social and existential /spiritual. Suffering is a subjective experience unique to the person who experiences it.²⁴ Most of the studies to date are quantitative in orientation and have focused mainly on the types of suffering rather than experiences of it.²⁴ All papers reported a lack of qualitative research into suffering and what it means to the individual patient and its importance in end of life care and decision-making. Indeed, a recent paper called for palliative care clinicians and researchers to '...Engage with the real issue: suffering and its healing'.²⁵ Given the brevity of qualitative research in this field, we report the findings from the analysis of a series of 49 focused narrative interviews with UK palliative care patients which sought to explore their views on the nature of suffering and what suffering meant to them as individuals. Four research questions underpinned this study:

- (1) How do individual patients define and make sense of suffering?
- (2) What are the factors that influenced patients' perception of suffering?
- (3) How were they able to manage their own resources to manage this?

- (4) To what extent do the above definitions of suffering support the findings from this study

Methods

Setting

The study was carried out in five hospice day units in North West of England between 1 November 2009 and 20 December 2010. This study received full ethical approval from the National Research Ethics Service (NRES) (Reference 09/H1017/95).

Participants

Patients with a diagnosis of advanced cancer (defined as advanced progressive disease) attending palliative care services were eligible to take part in the study. Those with severe cognitive impairment or dysphasia at recruitment (as judged by clinicians), under 18 years of age or with an insufficient understanding of the English language to complete the measures or the intervention were excluded from the study. Purposive sampling was used to recruit participants to the study to achieve maximum variation with regards to socio-demographic and clinical characteristics in order to identify core/central experiences of suffering. The sample size in this study was determined by the theoretical saturation of the data. This means that data collection ceased when no new or relevant data seemed to emerge in relation to a category or a theme. This sampling technique is theoretically informed and relevant to the research question. It also minimises the possibility of bias from selecting a convenient sample.²⁶

Procedure

Eligible patients were informed about the study by the means of a letter. Patients who agreed to be contacted by the researcher

received detailed information about the study and were asked to give written consent. Patients recruited into the study were invited to participate in a focussed narrative interview. The location of the interview was a venue convenient to the participant, usually the patients home or the palliative day care centre. Demographic information related to the sample including age, gender, marital status, ethnicity, disease type and whether depression and/or anxiety disorder were present prior to the cancer diagnosis were obtained from the patient or the patients records. Information about attrition and date of patient death was also recorded. The researcher prompted the patient to discuss perspectives on their sense of 'meaning', regarding suffering and their physical, psychological and spiritual well-being. In contrast to semi-structured interviews where the researcher follows an interview guide the emphasis was on allowing the patient to tell their story. The prompt guide (Table 1) was developed from the literature and was non-prescriptive.

In reality, patients did not require many prompts and talked extensively with little interruption from the interviewers. Patients were encouraged to share what they believed was the main factor for their suffering and to share what resources they themselves had employed in addition to what support they may have received. The pace, sequencing and duration of the interview was dependent on the patient. Patients were made aware that they could stop the interview at any time (or take breaks) if they felt tired or distressed. Any patient who became distressed (or had distressing symptoms) was referred onto the day care nurse and followed up and managed according to clinical practice and a concerns form was completed by the researcher. The researchers carrying out the interviews were trained in qualitative interviewing techniques and digital recordings were monitored and listened to by the chief investigator to ensure consistency and rigour.

Analysis

The qualitative narrative interviews were analysed to determine factors in concept of suffering and distress. All interviews were digitally-recorded, anonymised and transcribed verbatim and included hesitations, 'ums' and 'ers' and repetitions. The transcripts were analysed using thematic analysis²⁷ and this was continued in parallel with data collection, to identify factors that influenced patients' perception of suffering and how they themselves were able to utilise their own resources to manage this. All transcriptions were coded thematically using NVivo 7 Qualitative analysis software. The thematic categories were labelled using descriptive terms. An analytic matrix was created and searches were made for similarities and differences among participants' interpretations of the events in their lives. Comparisons were made both within and across cases. The majority of themes were emergent in the narratives provided by the participants, although others were driven by prompts. Narrative summaries were written for each participant. Following initial coding of the interviews, selected major themes were examined by two members of the research team independently. The two interpretations of the data were similar, with themes being identified by both the researchers and chief investigator developed and tested the analysis by regular discussion in order that the data met the accepted criteria for trustworthiness of qualitative analysis. These subthemes were discussed, developed and organised according to how the participants identified suffering.

Results

Demographics

Forty-nine patients attending palliative day care services were recruited into the study. Mean age was 65.8 years (age range 31–89 years) and 28% were male. The most

Table 1. Prompts guide for focused narrative interviews.

-
- What aspects of your life are most important to you?
 - Has having cancer changed how you think about your life?
 - Some people have told us they find it hard to make sense of what has happened to them – that they feel it's not fair, or they ask why me? Why now?
 - Is this important to you?
 - Is hope important for you? What do you hope for?
 - Has this changed since you found out about the cancer?
 - In an overall general sense, do you feel you are suffering?
 - If you tried to explain to someone your suffering – could you describe it?
 - What has helped to reduce your suffering?
 - What resources have you drawn upon to cope with your suffering?
 - How did you cope with difficult times in your life before you had cancer?
 - Has having cancer changed how you cope with things in your life?
 - Does faith or spirituality play a part in your life? In what way?
 - Can you tell me more about that?
-

common cancer diagnoses were breast cancer (24%), colorectal cancer (16%) and lung cancer (22%). The ECOG performance status of 75% of patients was one or two. Thirty-seven percent of patients had been diagnosed with depression or an anxiety related disorder before the cancer diagnosis. Ten patients (20.4%) died within 3 months of recruitment: the median survival of patients was 58.5 days (range 10–262 days). Of the patients interviewed, 98% described themselves as White British and 58% were married.

Generated themes

One overall theme and three subthemes emerged from this study and suffering held a number of different meanings for participants. These interpretations determined what suffering meant to them as individuals, how they perceived suffering had changed them as individuals and how it related to other feelings and emotions. While we have presented them as discrete themes they were interrelated.

The unavoidable and avoidable suffering. For some patients suffering was a normal part

of everyday life, experienced by everyone at some point and the suffering experienced in terminal illness was an unavoidable part of that process. This perspective appears to be primarily driven by the uncontrollable givens in life–death and perpetual change. For some, having a terminal illness served as a ‘*momento mori*’, a sharp reminder of mortality which in turn triggered suffering. Others felt suffering existed independent of having a terminal illness, which in itself did not add to ones perceived suffering.

Everyone suffers, whether it's from cancer or relationships... everyone suffers... So why should we be any different?...I see it as the norm...Everyone – if you look into their life – they've got something that causes them pain... whether it's physical pain or emotional pain, they've got something...And it's suffering! (female, 31 years, cancer of the breast)

Cleary, there were those that felt that suffering could be eased or even avoided if the right decisions were made and that mental strength was a means to prevent suffering. Others denied experiencing any suffering at all. These experiences may be related to anticipatory grief prior to the

impeding loss or even a rehearsal of death itself.

I'm not suffering no I don't feel that I've ever suffered. Mental uh mental strength is a lot to do with me. I've got a lot of fortitude you know in that way like I said to you it's coming from my family and how I've been brought up you get on with things you. I was talking to an aunt yesterday she's 80 she had a bad fall and she's lucky she's not broke anything, 'I'm alright' she says 'I'll be ok in a couple of weeks'. (male, 53 years, cancer of the prostate)

Cos I'm not ill. I suppose I'm not as physically... I'm not doing as much because I would always walk E (dog) myself but now 9 times out of 10 M (son) or R (husband) will do it. Umm I do go to my yoga once a week but I don't do as much as I did before. (female, 63 years, cancer of the ovary)

Physical and emotional suffering. Physical and emotional suffering appeared to be linked both avoidable and unavoidable suffering. The relationships between physical and emotional suffering often held important meaning as to the origin, process and meaning of suffering for participants. Some respondents differentiated between physical and emotional suffering. For those who perceived themselves as solely suffering physically, this manifested in physical pain without any emotional components. This kind of suffering often manifested itself in physical pain and limitation of movement.

I mean I can honestly say that I'm not really suffering because I take things as a prevention rather than waiting until I've got something and then taking.. I can hold it at bay so I don't suffer really. Well if I do suffer at all it's more of a physical thing really. .. No I'm quite sort of placid. People might argue against that but I think I am (laughs). (male, 46 years, cancer of the oesophagus)

Well I'm not in any great pain. ... So, I find that hard to answer. if I was suffering with pain of discomfort like that, erh then I'd say I was suffering. But I'm not suffering. ... To me it's just physical. (female, 83 years, cancer of the lung)

I suppose there's different 'what's the names 'of suffering. ... suffering that you hurt and suffering that you don't hurt um... or let's say suffering where you're in a lot of pain and suffering where you're suffering but you're not in pain. (female 72 years colon cancer)

Others had a more global view of suffering, some referring to pain in its broadest sense. Some participants described physical suffering as being disease specific. Only those who had had the disease had the ability to really understand the nature of this suffering, both physical and mental.

They think that they're the same as you- they don't understand either mentally or physically and always said when I had breast cancer when I was ill the first time, people were always saying 'oh yes I know what you mean'... they don't know. ... like somebody... I know what I mean by cancer but I don't know what anybody means that's had a stroke. (female 46 years cancer of the breast)

Suffering as loss. Suffering as loss also appeared to be associated with unavoidable suffering. Being faced with death was expressed by many as the ultimate manifestation of suffering as this encompasses suffering as both emotional and physical loss: that to suffer through loss was to anticipate the loss of the one you love.

...Umm I just feel sometimes you know the hurt that I've given to my husband and the boys. Umm... and they're going to have to cope afterwards... That's what hurts the most. (female, 43 years, cancer of stomach)

For some, it was sensing a loved one's emotional pain that represented the ultimate loss. In turn, this brought about profound sadness and guilt culminating in ruining normal attachments and expectations in relationships.

Umm well yeah if I was in a lot of pain definitely if umm... seeing my family suffer looking at me .. not being able to be in control of my own destiny . I suppose it's true now anyway but it's a bit in the future hopefully. (female, 63 years, cancer of the breast)

Suffering for me. its leaving the kids behind. (female, 31 years, cancer of the breast)

I have suffering to a certain extent, because of this, but I'm also suffering in my heart because of my family. (female, 31 years, breast cancer)

However, for some their religious beliefs and values brought a sense of comfort and hopefulness for the future.

I work hard at trying to be a decent person umm I really do believe in God and I'm not frightened of dying... I've said well you know 'Save me a place there I'll be there sooner than you think' sort of thing but umm you know I feel as though I'm going to see all those people again .. you know that I'll be saving a place for R (husband) .. I get emotional talking about these sorts of things. (female, 63 years, cancer of the breast)

For some participants the loss was a perceived as a disruption to normal physical functioning e.g. not being to complete ones normal activities of daily living.

um...yeah...yeah, it is...[long pause], yeah cos it...it holds you back, you know um...physically and...and emotionally um... but I...I'm...I mean I'm getting used to it now... like um...it is...um... it's difficult coming to terms with the fact that you can't do some of the things you

were doing before. Well initially I thought about it (suffering) being...extreme stress...through terminal illness but... it's anything really that...that stops you from feeling as though your life is normal I suppose. (female, 58 years, cancer of the breast)

For some the loss of normal functioning became a threat to their dignity and independence. A number of participants described this in the context of family. One participant identified situations of feeling like a burden on them.

I've always been able, independent, always. I find it awfully difficult not to be independent.to ask people to do anything. I always have a vase of flowers on...now I can't empty the water with bowls of flowers because I can't carry it from the living room to the kitchen. So I always have to ask a carer to take it in for me. I'll rinse it out, um strip the flowers, you know, make them fresh and that and then the next carer comes in, I have two a day.... she'll bring it back in for me. I find that awfully frustrating. (female, 66 years, cancer of colon)

... well the fact that for example I am not able to work for myself and earn some income well obviously that one it affects anybody who doesn't like to be dependant. If you could help it you would like to be independent work for yourself earn your own living honestly and uh here and there help make a contribution to society that your mind tells you is worth making but I am totally dependent on society. But I say I have to accept it because there is no option. (male, 61 years, cancer of prostate)

Moreover, decreased normal functioning appeared to affect the sense of personal value subsequently further decreasing self-worth and in some, bringing about a sense of total hopelessness causing a deep loss in an existential context.

If there's no hope for you and they've said that they can't do anything for you, then I

don't think you should suffer too much;
just let somebody put you to sleep. (male,
61 years, cancer of colon)

Transformation through suffering. Transformation through suffering was again linked to unavoidable suffering. For some participants the experience of suffering was transformative, an event that altered their view on self or how they viewed the world in a fundamental way. For many this transformation was spiritual in nature, enabling them to discover their very deepest essence of being. To this end, spirituality became a lens through which a person could understand and live with his/her own suffering, the outcome of which was to develop a more coherent self and sense of meaning. For some the transformation was approached through a more religious transcendence.

I haven't gone to church. I did think about it when I first came out of hospital. I did think about going to church but the stronger I got the more it went into the background.but I must admit I have prayed to God to thank him for being here.No I wasn't religious before, I mean we've been at Christmas and things, go to weddings and things but I wouldn't say we were religious but I certainly have thanked him since I've been home. (male, 66 years, cancer of lung)

Discussion

In this qualitative study, using focused narrative interviews, we explored the nature of suffering and what suffering meant to them as individuals in 49 palliative care patients, many of whom were in the last few weeks and months of life. The analysis revealed that for many patients although clearly unwell and close to death, there did not appear to be a sense that they were suffering. Although this finding is comparable with a recent study,¹ it is in contrast to earlier

ones.^{3,6,28,29} For those patients who perceived they were suffering, this study revealed a wide spectrum of interrelated definitions which could be described within the following areas; the unavoidable and avoidable suffering, physical and emotional suffering, suffering as loss and finally transformation through suffering, which appear to compliment the two definitions of sufferings outlined in this paper. These interpretations were context-bound and determined what suffering meant to them as individuals, how they perceived suffering had changed them and how it related to other feelings and emotions. This is in contrast to much of the suffering literature which is essentially quantitative and reductionist in nature in that it seeks to establish some sort casual connection between the different dimensions of suffering.

For some respondents in this study, suffering appeared to be a normal part of everyday life and unavoidable such as pain being part of everybody's life and things change.³⁰ To an extent, this view of suffering may reflect people's religious beliefs as some faiths (e.g. Christian and Buddhists) consider suffering an inevitable component of human life and both discern potential purpose within suffering. Suffering can be taken on or 'offered up' for the sake of others in distress. In both traditions, suffering can serve to free the person from the imperfection of human existence, providing a means of coming to God in heaven or of achieving enlightenment.⁴

Having a terminal illness was also a reminder of mortality, which triggered suffering. Yet some felt that suffering could be eased and even avoided if the right decisions were made and mental strength was expressed as a means to prevent suffering. For those who perceived themselves as solely suffering physically, this manifested in physical pain without any emotional components. This was comparable with those studies that view pain and suffering

as separate entities.³ A few participants defined physical suffering as being disease-specific and added that only those with cancer would understand. To our knowledge, this has not been noted in other studies which have explored suffering.

Being faced with death was expressed as the ultimate manifestation of suffering as this encompasses suffering as both emotional and physical loss. The emotional loss was perceived to encompass a loss of control of destiny, loss of a future, anticipating and feeling the loss family and friends would experience, worrying how they would cope afterwards, leaving and feeling the projected loss of their own children and loved ones, and also the sensing of their emotional pain. Apart from the actual pain, the physical loss was perceived as losing the ability to complete normal daily activities, hence a disruption to normal physical functioning. This could be conceptualised as a biographically disruptive event, functioning as a mode for explaining pain and suffering. Individuals who experience a biologically disruptive event sense further loss as they strategically withdraw from social interaction.³¹ Subsequently, losing the ability to function or continue in their usual roles, which disrupts the way they see themselves and then self-congruence is also lost^{2,32} as reflected in this study.

Our analysis also revealed how loss of normal functioning became a threat to dignity and independence for some patients, which resulted in perceptions of being a burden on family and carers, ultimately undermining the value of life itself since dignity is seen as indivisible from a person's core being or essence.¹⁶ Moreover, decreased normal functioning appears to affect the sense of personal value subsequently further decreasing personal value and in some bring about a sense of total hopelessness in an existential context. Additionally, the uncertainties that accompany a terminal prognosis and subsequently

an existential crisis often culminate in an adjustment disorder with anxiety.⁷

Such findings are important: an investigation into the dignity model revealed that patients with a sense of diminished dignity were most likely to experience and symptom distress, decreased quality of life, heightened dependency needs, loss of will to live, increased desire for death, depression hopelessness and anxiety.¹⁴ Results from others indicate that participant who report feel depressed and those whose physical health status deteriorates to such a degree that they are dependent on caregivers for support may be the most vulnerable to a loss of dignity.³³

Absolute hopelessness where life has no intrinsic meaning or value can lead to a mood of despair at a perceived pointlessness of existence, which Schopenhauer referred to as 'Passive Nihilism'³⁴ – the separating of oneself of will and desire in order to reduce suffering. Only one respondent in our study stated if there was no hope, then let somebody '*Put you to sleep*', in other words wanting to hasten death. This supports previous findings stating that hopelessness and loss of control are associated with a heightened interest in death-hastening measures.^{9,10,16,29} Although it may be argued that there is a relationship between suffering from severe pain and the desire for hastened death in patients with advanced cancer, pain has not been found to be an independent cause.⁹ Interestingly, a recent Chinese study³⁵ found that for many patients pain served as a critical reminder that they were still living, although this was not something that was reflected in our findings. An explanation for this may be that as this was a Chinese study this particular finding may be associated with the beliefs and values within that particular culture. Studies have also shown that suffering with severe pain correlates significantly with depression and/or anxiety³⁶ and is coupled with hopelessness and loss of control. It also follows that there is a correlation between the terminally

ill patients' strong desire to hasten death, and depression, symptom severity and hopelessness.⁹

A transformation through suffering, predominantly spiritual in nature, led to greater and deeper understanding of themselves providing a spiritual view enabling ability to cope, understand and accept suffering, and a more lucid self and sense of meaning. For some patients, this developed into a more religious transformation. It could be argued that this subtheme supports the findings that although not all patients are religious, most (if not all) are spiritual. In some cases, this involved acceptance of a smaller sphere of personal control through which to act. Accepting a smaller sphere may be a useful coping strategy in that it minimises concerns and maximises ability to act within the new smaller sphere. In turn, this raises important questions as to how continuity of care impacts on patient experience.

Such findings may be important when examining suffering in the clinical context. Psychologists have acknowledged this transformation and have termed it 'post-traumatic-growth' (PTG).³⁷ PTG typically features a change in general perception, self-perception and attitude to life, including philosophical/spiritual changes.³⁸ Patients who experienced traumatic life events such as having cancer were interviewed by Tedeschi and Calhoun³⁷ who found that many respondents dealing with trauma gained a 'powerful spur' for personal growth, which was not just a case of adjusting or coping but they underwent positive life changes and gained new inner strength. They predominantly developed a more spiritual attitude and a deeper level of awareness. Transformation appeared to be brought about by a sequence of events whereby their previous values were thrown into question and life ceased to have any meaning: a time of spiritual searching followed by new spiritual principles to live by and finally entered a phase of spiritual integration as

they applied these new principles. Our findings would tend to support this.

Strengths and limitations

We believe this study is not only the largest UK qualitative study but it is also one of the few that explores suffering and what suffering means to individual patients and its importance in end of life care and decision-making, which are key strengths of this study. This study also included a wide age range of patients and the median survival of patients was 58 days. All patients were recruited into this study from hospice day units where holistic care is the norm and attention is paid to the physical, psychological and social determinants of suffering. It could therefore be argued that suffering for patients participating within this study was already being addressed by virtue of fact they were attending a hospice. The findings of the study may have revealed a greater sense of suffering if patients had been recruited from other settings e.g. primary care, hospital or care homes. The lack of ethnic diversity in our sample limits the extent to which the findings can be generalised with a markedly different racial and ethnic composition. Therefore, further research with a more diverse group of participants, from different settings, is required to explore these factors more fully.

Implications for practice

The findings have a number of implications for practice which are outlined below:

- It is important to consider the whole person, rather than the narrow aspects such as physical symptoms, manifestations of distress or spiritual concerns as this is critical to understand suffering. Consequently, interventions to alleviate suffering require an integral view of the person's experience.

- Given that suffering is dynamic in nature and a subjective experience, the findings from this study support the need for frequent and tailored assessment of the patient (and family's needs) and perceived threats. Additionally, physical, psychological social and spiritual issues should be identified and attended to.
- Clinicians should not only consider the presence of a problem but also the meaning given by individual patients at a particular point in time.

Conclusions

This study reveals that the concept of suffering is much more complex than many other studies would suggest. Crucially, some participants seem to experience transformation through suffering and through this transformation, many of the coping skills evolved, such as; gaining a more spiritual perception of life, which in turn gave more meaning and acceptance to life, self and suffering. It is imperative therefore that holistic care is offered to all patients with life-limiting disease and that patients are also given opportunities to express their feelings regarding suffering. True holistic care may not be able to palliate all the components of suffering; however, allowing the patients the space and time to verbalise and possibly make sense of their situation can allow patients to feel supported, valued and retain their sense of dignity.

Conflict of interest

None declared.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

References

1. Wilson KG, Chochinov HM, McPherson CJ, et al. Suffering with advanced cancer. *J Clin Oncol* 2007; 25: 1691–1697.
2. Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med* 1982; 306: 639–645.
3. Baines BK and Norlander L. The relationship of pain and suffering in a hospice population. *Am J Hosp Palliat Med* 2000; 17: 319–326.
4. Ferrell BR and Coyle N. The nature of suffering and the goals of nursing. *Oncol Nurs Forum* 2008; 35(2): 241–247.
5. Daneault S, Lussier V, Mongeau S, et al. The nature of suffering and its relief in the terminally ill: A qualitative study. *J Palliat Care* 2003; 20: 7–11.
6. Benedict S. The suffering associated with lung cancer. *Cancer Nurs* 1989; 12: 34–40.
7. Holland JC. Anxiety and cancer: The patient and the family. *J Clin Psychiatry* 1989; 50: 20–25.
8. Frankl VE. *Man's search for meaning* (Rev. ed.). New York: Washington Square, 1984.
9. Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA* 2000; 284: 2907–2911.
10. Chochinov HM, Wilson KG, Enns M, et al. Depression, hopelessness, and suicidal ideation in the terminally ill. *Psychosomatics* 1998; 39: 366–370.
11. Kissane DW, Clarke DM and Street AF. Demoralization syndrome—a relevant psychiatric diagnosis for palliative care. *J Palliat Care* 2000; 17: 12–21.
12. Chochinov HM. Dying, dignity, and new horizons in palliative end of life care. *CA: Cancer J Clin* 2006; 56: 84–103.
13. Chochinov HM. Dignity and the essence of medicine: The A, B, C, and D of dignity conserving care. *BMJ* 2007; 335: 184–187.
14. Chochinov HM. Dignity-conserving care—a new model for palliative care: Helping the patient feel valued. *JAMA* 2002; 287: 2253–2260.
15. Rosenfeld B. Suicide, assisted suicide, and euthanasia in the terminally ill. In: Chochinov HMC, Breitbart W (eds) *Handbook of psychiatry in palliative medicine*. New York: Oxford University Press, 2000, pp.51–62.
16. Seale C and Addington-Hall J. Euthanasia: Why people want to die earlier. *Soc Sci Med* 1994; 39: 647–654.
17. Bury M. Chronic illness as biographical disruption. *Sociol Health Illn* 1982; 4: 167–182.

18. Charmaz K. Loss of self: A fundamental form of suffering in the chronically ill. *Sociol Health Illn* 1983; 5: 168–195.
19. Charmaz K. The body, identity, and self. *Sociol Quart* 1995; 36: 657–680.
20. Charmaz K. *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press, 1991.
21. Charmaz K. Identity dilemmas of chronically ill men. *Sociol Quart* 1994; 35: 269–288.
22. Hutto DD. Narrative and understanding persons. *Roy Inst Philos Suppl* 2007; 60: 1–16.
23. Reeve J, Lloyd-Williams M, Payne S, et al. Revisiting biographical disruption: Exploring individual embodied illness experience in people with terminal cancer. *Health* 2010; 14: 178–195.
24. Beng TS, Guan NC, Seang LK, et al. The experiences of suffering of palliative care patients in Malaysia: A thematic analysis. *Am J Hosp Palliat Med* 2014; 31: 45–56.
25. George R. Suffering and healing—our core business. *Palliat Med* 2009; 23: 385–387.
26. Mays N and Pope C. Qualitative research: Rigour and qualitative research. *BMJ* 1995; 311: 109–112.
27. Riessman CK. *Narrative methods for the human sciences*. London: Sage, 2008.
28. Kuuppelomäki M and Lauri S. Cancer patients' reported experiences of suffering. *Cancer Nurs* 1998; 21: 364–369.
29. Ganzini L, Johnston WS and Hoffman WF. Correlates of suffering in amyotrophic lateral sclerosis. *Neurology* 1999; 52: 1434.
30. Richo D. *The five things we cannot change: And the happiness we find by embracing them*. Boston, MA: Shambhala Publications, 2008.
31. Strauss AL, Corbin J, Fagerhaugh S, et al. *Chronic illness and the quality of life*. St Louis: Mosby, 1984.
32. Byock IR. The nature of suffering and the nature of opportunity at the end of life. *Clin Geriatr Med* 1996; 12(2): 237–252.
33. Hack TF, McClement SE, Chochinov HM, et al. Learning from dying patients during their final days: Life reflections gleaned from dignity therapy. *Palliat Med* 2010; 24: 715–723.
34. Critchley S. Passive nihilism. *Philos Magaz* 2010; 2010: 36–37.
35. Ho AHY, Chan CLW, Leung PPY, et al. Living and dying with dignity in Chinese society: Perspectives of older palliative care patients in Hong Kong. *Age Ageing* 2013; 42: 455–461.
36. Spiegel D, Sands S and Koopman C. Pain and depression in patients with cancer. *Cancer* 1994; 74: 2570–2578.
37. Tedeschi RG, Park CL and Calhoun LG. *Posttraumatic growth: Positive changes in the aftermath of crisis*. New York: Routledge, 1998.
38. Fosse MJ. Posttraumatic growth: The transformative potential of cancer. Massachusetts School of Professional Psychology, 2005.